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ABSTRACT

This report examines issues concerned with the use of aversive behavior modification techniques in actual treatment practices at one intermediate care facility for the mentally retarded. The review of these practices reveals how, once the philosophy of using aversives takes hold at a program (to deal with seemingly intractable behaviors), its "success" can easily lead to a wider application of an increasing array of aversive techniques to less severe behaviors, without any attempt at more conventional treatment approaches which pose less risk of harm to clients. Recommendations to insure adequate safeguards for clients are offered and include securing the consent of the specific client if competent to provide consent, gaining permission for the use of aversive interventions from a body external to the facility, and permitting the aversive intervention only after proof of the dangerousness of the targeted behavior and the ineffectiveness of other treatment interventions. Responses to the report from the Office of Mental Retardation and Developmental Disabilities and from the Board of Directors of the institution investigated are appended. (DB)

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Abusing the Unprotected:

A Study of the Misuse of Aversive Behavior Modification Techniques and Weaknesses in the Regulatory Structure

NYS Commission on
QUALITY OF CARE
for the Mentally Disabled

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Abusing the Unprotected:

A Study of the Misuse of Aversive
Behavior Modification Techniques and
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PREFACE

The use of aversive behavior modification techniques* to rid developmentally disabled persons of undesirable behaviors has been a subject of great controversy in the professional community and in public debate. Proponents of aversive programming point with pride to the success of their techniques in correcting harmful or antisocial behaviors that previously had been thought to be immune to change. Opponents cite the painful and sometimes harmful and degrading nature of the techniques used; their use to eliminate seemingly non-dangerous behaviors, and the absence of meaningful protections to ensure that disabled persons are not abused in the name of treatment.

The Commission's review of the use of restraints and aversive behavior modification techniques with developmentally disabled clients at Opengate, an Intermediate Care Facility for the Mentally Retarded, examines these issues, which are often debated in the abstract, in the context of the concrete reality of actual treatment practices. The review reveals how, once the philosophy of using aversives takes hold at a program (to deal with seemingly intractable behaviors), its "success" can easily lead to a wider application of an increasing array of aversive techniques to less severe behaviors, without any attempt at more conventional treatment approaches which pose less risk of harm to clients.

The risks of the routine use of painful and potentially harmful "treatment" practices warrant the strongest and most vigilant regulatory oversight to protect vulnerable clients from harm. This is particularly so since the clients themselves are often unable to play a meaningful part in their treatment planning or to protect themselves from such treatment. While the need for vigilance is great, so are the impediments to effective monitoring. Families and guardians experience such difficulty in obtaining residential placements for developmentally disabled clients with severe behavior disorders that they often have very little real choice but to acquiesce in proposed treatment practices at a facility that they see as their only alternative. Boards of directors of not-for-profit provider agencies often lack the knowledge of their legal obligations and responsibilities and frequently do not have effective procedures for keeping themselves informed about significant aspects of program operations. Even if in-

* Aversive conditioning is defined in regulations as "the planned use of stimuli or events considered by the client to be unpleasant and painful, with the intent to decrease the frequency of a maladaptive behavior."

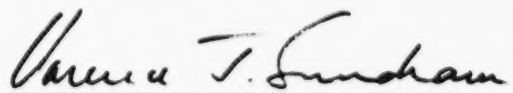
formed, they often lack knowledge of available program options to those proposed by the agency's professional staff. (See *Pitfalls in the Community-Based Care System: A Review of the Niagara County Chapter NYS Assocaition for Retarded Children, Inc. and Agencies Responsible for its Oversight*, September, 1984; *Profit Making in Not-for-Profit Care: A Review of the Operations and Financial Practices of Brooklyn Psychosocial Rehabilitation Institutes, Inc.*, November 1986.) Finally, when the regulatory agency is significantly influenced in its behavior by its simultaneous role as a provider of last resort, its ability to provide such strong and vigilant oversight is substantially weakened. In this instance, although OMRDD was aware in December 1981 of numerous violations of the law governing the use of restraints by Opengate, five years have passed and it has not yet adopted a clear and consistent policy on this subject. Proposed regulations have only recently been promulgated for review and comment.

This review of Opengate is instructive as well in understanding an important truth. Effectiveness alone is not a valid test of an aversive behavior modification program. The Commission readily acknowledges that, when faced with consistently painful and unpleasant consequences, people will change their behavior, at least temporarily. The question is whether a desired change in behavior can be achieved without exacting such a toll on the human dignity of both clients and the staff involved.

Despite the spirited defense by Opengate's former Executive Director of the range of aversives used and of the absolute necessity of such aversives to rid clients of undesirable behaviors, a new administration at Opengate has discontinued the use of all aversives. Rather than the predicted regression and deterioration of the clients' behaviors, the Commission's ongoing monitoring of conditions indicates that residents' behaviors are responding to the new emphasis on skill-building, to the focus on appropriate behavior and to the sense of being valued which has been provided by interacting with caring staff.

In this report, the Commission offers recommendations to guide the development of state policy to ensure that vulnerable citizens are protected from harm.

The findings, conclusions and recommendations represent the unanimous opinions of the members of the Commission. The responses of the Office of Mental Retardation and Developmental Disabilites and Opengate's Chairman of the Board are attached to the report.



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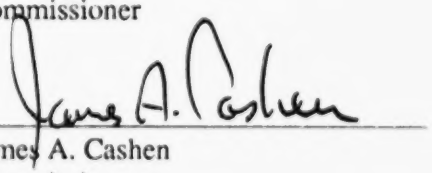

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INTRODUCTION

Opengate, Inc., an Intermediate Care Facility (ICF) located in Somers, New York, serves approximately 30 developmentally disabled adults, many with either a secondary psychiatric diagnosis or, lacking a particular secondary diagnosis, a significant behavior problem. In addition to residential services, Opengate also provides day programming for its residents because, according to the facility administration, many of the residents have been dismissed from or would be denied admission to other programs due to their aggressive or self-injuring behaviors.

Beginning in 1982, the Commission has had concerns about the facility's use of a camisole (straightjacket) to control the behaviors of several of its developmentally disabled residents. Using the camisole with this population is an uncommon practice in New York State and one which is generally considered an inappropriate form of treatment by the Office of Mental Retardation and Developmental Disabilities (OMRDD) as evidenced by the prohibition against its use in developmental centers (OMRDD Policy and Procedures §5.5.2). Our concerns were documented in oral and written communication with the facility and shared with the OMRDD with requests that, as the certifying agency, it review the situation and take appropriate remedial action.

In December, 1984 the Commission received an anonymous complaint alleging that, in addition to the use of the camisole, Opengate had begun to use other restraining devices and aversive techniques (the application of unpleasant or painful stimuli) to modify clients' behaviors.

After alerting the OMRDD to these allegations in January, 1985, researching State rules and regulations on the use of restraint and aversives with the developmentally disabled, interviewing the complainant and other individuals associated with the facility, the Commission made an unannounced visit to the facility. During the March 12, 1985 visit, three Commission staff members toured the facility, reviewed the records of four clients, spoke with the Executive Director and other senior facility staff and with several residents. At the conclusion of the review, it was clear that in its use of restraint, seclusion and aversives, Opengate was in violation of pertinent sections of the Mental Hygiene Law, in violation of regulations governing the operation of ICF-MRs, and was subjecting the affected residents to systematic mistreatment.

It was also apparent that Opengate offered its residents a severely limited number of active programming options and, consequently, was not meeting the diverse educational, vocational and recreational needs of the residents. Finally, there was evidence that Opengate was denying residents their right to associate with individuals of their choice, protected by Federal ICF-MR regulation [442.404 (f)] by denying family visits without clinical justification.

Because of the serious nature of the findings of legal violations and programmatic inappropriateness of the use of restraints and aversives, coupled with the facility's strong commitment to the continued use of such techniques, the Commission questioned the ability of the staff and administration to carefully consider the programmatic, legal and ethical questions inherent in the use of such aversive behavior modification techniques. The findings also raised questions about the role of the Board of Directors in setting agency policy and of the OMRDD, as the certifying agency, in evaluating and effectively monitoring the program. However, as the Opengate administration clearly had no intention of correcting the abuses of its aversive conditioning and, indeed, saw nothing improper in its practices, the Commission issued a preliminary report of its findings to Opengate's administration, to its Board of Directors and to the OMRDD. The Commission also undertook a more extensive review of the OMRDD's regulatory and oversight processes relative to the issues of restraint and aversive conditioning generally and at Opengate specifically.

While the Commission's March, 1985 review conclusively documented Opengate's lack of compliance with statutes and regulations governing the use of restraints and aversives and identified Opengate's dearth of active programming, it did not address two seminal questions — Did the residents of Opengate, in fact, require the use of aversives to control their behavior and, if aversives were necessary, what safeguards should be established to insure their ethical and therapeutic use? To help in exploring these issues, the Commission enlisted the assistance of Dean L. Fixsen, Ph.D. of Omaha, Nebraska, well known for his writings and research in the field of behavior modification. The Opengate Board of Directors, in response to receipt of the Commission's preliminary findings, also sought an independent evaluation of the facility's aversive conditioning program. Through reviews of the reports of these two consultants, reviews of subsequent OMRDD visits, and periodic visits by its own staff — all of which generally confirmed the Commission's preliminary findings — the Commission monitored conditions at Opengate during the period from March, 1985 to April 1986. During this thirteen month period, the facility changed its senior administration and substantially altered its treatment focus.

Organization of the Report

The two chapters of this report represent the dual focus of the Commission's review. Chapter I presents the findings of the March, 1985 visit and the facility's reemergence a year later with a new administration and changed philosophy. Chapter II discusses the weaknesses in the OMRDD's regulatory and oversight functions brought to light by the Opengate review and offers the Commission's recommendations to ensure the humane use of aversives, when necessary.

CHAPTER I
Opengate: March, 1985

Prompted by allegations that Opengate had expanded its use of restraint beyond the camisole to hand restrictors (handcuffs) and a time-out chair, and had begun to use seclusion and several other aversive procedures to modify residents' behavior, Commission staff members visited the facility in March, 1985. The review substantiated that the allegations were accurate and confirmed, additionally, that Opengate intended to expand its use of aversives shortly to include a larger repertoire of techniques and to apply those techniques to a larger proportion of its students. Commission staff members were able to view and, in some cases, try on the restraint devices, such as the hand restrictors and time-out chair; experience confinement in the time-out room; and, walk through the residential and programming sites on campus. Additionally, CQC staff were able to speak with several residents. The time spent with the Executive Director provided him the opportunity to explain the reasons for the initiation of the aversive program and to indicate his plans for its expansion. The hours spent with the case records enabled CQC staff to review Opengate's documentation of the behaviors for which aversives and restraint were prescribed; the procedures followed in the application of these techniques; the frequency and duration of their use; the position of aversives and restraint in the total treatment plan; and, the extent of the consent granted by parents and guardians for their administration.

The review confirmed that in its use of restraint, seclusion and aversives, Opengate was failing to meet the requirements set down by state law and ICF-MR regulations that safeguard residents from abuse of these potent and unpleasant behavior management measures. Additionally, residents were denied visits from their families with no clinical justification. The review also revealed that residents and their families were not given sufficient accurate and client-specific information upon which to base their consent for the use of restraint and aversives. Finally, the review uncovered a serious lack of programming options to meet the residents' educational, social and vocational needs and to foster appropriate prosocial behaviors.

Law and Regulation

Mental Hygiene Law, Section 33.04, in defining restraint and prescribing the conditions under which it may be used and in specifying procedures governing its use, seeks ultimately to protect residents of mental hygiene facilities from abuses in the use of this treatment/management technique. According to Mental Hygiene Law [MHL, §33.04 (a)], restraint is the "use of an apparatus on a patient which prevents the free movement of both arms

or both legs or which totally immobilizes such patient and which the patient is unable to remove easily." The law also specifies that only the camisole and the full or partial restraining sheet or other less restrictive restraint authorized by the Commissioner are permissible forms of restraint [MHL §33.04 (c)].

In addressing the conditions under which restraint may be used, MHL, §33.04 (b) indicates that restraint may be employed:

- only when necessary to prevent a patient from *seriously* injuring self or others; and
- only if less restrictive techniques have been clinically determined to be inappropriate or insufficient to avoid injury. (Emphasis added.)

Furthermore, the law states that restraint may *not* be used as punishment, for the convenience of staff, or as a substitute for a treatment program.

Finally, in addressing the procedures for the utilization of restraint, the law requires the involvement of a physician. Specifically, the law requires that restraint, except in emergency situations, shall be effected *only* by a written order of a physician after a personal examination of the individual to be restrained. The physician's order should specify the facts justifying the use of restraint, the nature of restraint, conditions for maintaining the restraint, and the time of the expiration of the order which during the day time, may not exceed four hours [MHL §33.04 (d)].

In emergency situations where an individual presents an immediate danger and a physician is not immediately available, the law allows for restraint to be employed at the direction of a senior staff person. However, the senior staff person must ensure that a physician is summoned and record the time of the call and the person contacted. If the physician fails to respond within 30 minutes, the senior staff person must record the delay and the physician, upon his/her arrival, must document in the clinical record an explanation for the delay. Pending the arrival of the physician, the restrained individual must be kept under constant supervision [MHL §33.04 (e)].

Like Mental Hygiene Law (§33.04), Part 681 of Title 14 of the New York Codes, Rules and Regulations seeks to protect mentally disabled persons from the capricious use of certain treatment modalities. Specifically, Part 681 prohibits the use of seclusion for residents of ICF-MRs and sets parameters on the use of aversives. Aversive conditioning is defined in regulation as "the planned use of stimuli or events considered by the client to be unpleasant and painful, with the intent to decrease the frequency of a maladaptive behavior." Aversive conditioning is permitted when three conditions have been met:

- when a client's behavior is likely to cause serious physical danger to self or others;
- after positive reinforcement procedures and all other less drastic alternatives have been shown to be unsuccessful (as documented in the Individual Program Plan);
- with the approval for the aversive technique from the client (if capable of informed consent) and from the next-of-kin or guardian. (Emphasis added.)

Seclusion Disguised as Time-Out

The NYS regulations governing the operation of ICF-DD's expressly prohibit the use of seclusion, defined as the placement of a client alone in a locked room or in an area from which he or she cannot exit without assistance [14 NYCRR 681.13 (mm)]. Behavioral plans of some Opengate residents called for the placement of each of these residents (for up to two hours) in a "Time Out Room." Commission reviewers observed this room noting its restricting size (approximately 4' by 8'), grey padding and small viewing window in the door which could be covered from the outside by a sliding wooden panel. The room's lighting was controlled by a dimmer switch on the outside wall. Significantly, the door had no handle or knob on the inside and a lock on the outside. The presence of the lock on the door clearly illustrated the facility administration's failure to protect clients against potential misuse of the room and, in effect, sanctioned the misuse of time-out.

Use of Restraint and Aversives in the Absence of Dangerous Behaviors and in the Absence of Tried Alternatives

Similarities between several of the conditions set out for the appropriate use of restraint and aversives in law and regulation are striking, although not surprising. Both require that the techniques be employed only in the face of *serious* behaviors which threaten the physical well-being of the client or others. Additionally these techniques can be used only after less drastic measures have been tried and found unsuccessful (in the case of aversives), or have been clinically determined to be inappropriate or insufficient to avoid injury (in the case of restraint). Opengate failed to meet both of these criteria before employing restraint or aversives.

In the Commission's review of the four client records, numerous instances were found in which clients were restrained or subjected to aversives for behaviors which did not pose a threat of serious injury to self or others and which, in some cases, were innocuous.

One client, Linda Thompson*, had a behavioral program which called for her to earn tokens for periods of silence and to use them to purchase time to talk. If Linda talked out of turn and refused to pay her tokens, she was placed in hand restraints, which were applied to her arms behind her back. She would be released from the restraints after 20 minutes of silence.

Linda's case record was replete with other examples of restraint being applied in response to equally non-threatening behavior. Linda was also subjected to aversives for what can be described as common responses to everyday life situations. As an example, when Linda refused to get out of bed, she was first fined tokens earned for positive behaviors. If she continued to refuse to get up, an aversive was used—every five minutes she would be sprayed in the face with water until she got out of bed. If, during programming

* A Pseudonym

hours, Linda began to tantrum verbally (cursing, shouting, etc.), staff would break one of her cigarettes (which she had earned for positive behavior) and ignore her no matter what she requested or said. If Linda responded to this by leaving the classroom, she would be restrained by two staff (using hand restraints behind her back) and forced to inhale ammonia fumes for five seconds. Linda's record contained a note advising staff to ensure she inhaled the ammonia. Commission staff were informed by an Opengate employee that tickling a client was the suggested method for ensuring the fumes were inhaled.

Linda's was not an isolated case. Lara Smith's* screaming behavior (which posed no threat of physical harm to anyone) resulted in her being bound hand and foot in the restraint chair with a helmet placed over her head, severely limiting her vision and hearing.

It would be an unfair characterization of Opengate's use of aversives and restraint to suggest that in all instances, these measures were used in response to innocuous behavior. Sometimes, in the jargon of the treatment plans at Opengate, these measures were used in response to aggression — "person and object aggression." Unfortunately, the lack of specificity in this language made it difficult to determine exactly what specific client actions prompted the use of restraint or aversives. For example, on May 14, 1984 client Roy Barton* was placed in a camisole for what the record described as "object aggression." And on October 29, 1984 Linda was restrained for what was described as "person aggression." In such cases, with so little detail about the clients' behavior, it was impossible for the Commission—or for that matter, senior clinicians at Opengate—to determine whether restraints were justified by the likelihood of injury to clients themselves or to others.

Opengate's use of aversives as punishment further demonstrated the facility's disregard for the legal and regulatory restraints placed upon these interventions. The behavior plans for Sam Levine* and Roy Barton required that when each failed to verbally acknowledge their misdeed and/or refused to apologize or agree to cooperate, the length of time an aversive was used was extended. As an example, Roy Barton's behavior plan read as follows:

> When Roy became person or object aggressive, he was placed in hand restraints and seated. Staff said, "Roy, your behavior is irresponsible. Are you ready to accept responsibility for your behavior?" If Roy responded "yes," he was forced to inhale ammonia for three seconds, was sprayed with water for 30 seconds and again forced to inhale the ammonia for three seconds. Roy was then to thank staff for their help. If Roy responded negatively and did not accept responsibility for his behavior, staff repeated

* A Pseudonym

the ammonia, water spray, ammonia sequence again. If, asked again to accept responsibility for his behavior, Roy again refused, the aversive sequence was repeated twice in succession.

Clearly, failure to respond in a verbally appropriate manner to a request cannot be construed as behavior likely to cause serious physical injury to self or others. Use of aversives as punishment for non-serious behavior violated the protections guaranteed by state regulation (14 NYSCRR §681.4).

Mental Hygiene Law (§33.04) and ICF-MR Regulations (14 NYSCRR, §681), in addition to limiting the use of restraint as a response only for dangerous behaviors, also requires that restraint be employed *only* as a last resort, when less restrictive/drastic alternatives have been determined to be inappropriate or inadequate. In the review of four clients' records, Commission staff found no evidence to indicate that, as alternatives to restraint, less restrictive techniques of controlling behaviors were tried and proven inappropriate or inadequate. In fact, in one case it was found that Opengate developed a behavior plan calling for the use of the camisole on the date of the client's admission.

On August 28, 1984, the day Sam Levine was admitted to Opengate, a behavior plan was developed to positively reinforce four of Sam's appropriate behaviors and reduce six of Sam's maladaptive behaviors, including hitting, biting self or others, screaming, grunting or groaning, and running aimlessly about. This treatment plan called for the use of a camisole, hand restraints, and other aversives such as palm hit, time-out helmet, ammonia fumes and water sprays. The case record contained no indication that any less intrusive measures were even considered, and certainly none were tried.*

A similar situation, though less dramatic, occurred in the use of aversive conditioning with Linda Thompson, who was admitted to Opengate on June 4, 1984. A behavioral reduction plan was present in her case record for the period August 25, 1984 to August 15, 1985. Among the target behaviors to be reduced with aversives were: verbal tantrumming; refusing to get out of bed; threatening aggression; and becoming person or object aggressive. Repeated threats of aggression or actual aggression resulted in a minimum of ten minutes of hand restraint. Verbal tantrumming combined with leaving the class room led to hand restraints and five

* The scope of the Commission's record review varied depending on the client's length of stay at the facility. Three clients were admitted to Opengate between February, 1984 and September, 1984. In these cases, the review included all documents produced by Opengate dating back to the clients' admissions. In the fourth case, the client was admitted in January, 1983 and the record review focused on the past year of the resident's stay at Opengate.

seconds of ammonia fumes. Refusing to get out of bed in the morning earned water sprays in her face. Nine weeks, from June 4, 1984, the date of her admission until August 25, 1984 when the behavior plan was developed, comprised the total time available to Opengate to exhaust all less drastic alternatives to treat Linda's maladaptive behaviors. It is clear that even a *brief* trial of even a *few* alternate treatment methods would have required more than nine.

In sum, Opengate used restraint and aversives to control residents' undesirable behaviors — many of which were innocuous or at least posed no likelihood of serious harm to the resident or others. Additionally, Opengate failed to attempt the use of less drastic behavior management techniques for a reasonable period of time before it escalated its response and used either restraint or aversives. Both of these violations clearly circumvented safeguards in Mental Hygiene Law and ICF-MR Regulations against the capricious use of restraint and aversives.

The Use of Unauthorized Restraining Devices and the Absence of a Physician

Observation of Opengate's restraint practices and review of their restraint records indicated that unauthorized restraint devices were used, and that residents were not provided a physician's examination prior to being restrained, as required by Mental Hygiene Law, § 33.04.

Restraint devices are defined in Mental Hygiene Law as an apparatus which prevents the free movement of both arms or legs or which totally immobilizes an individual. At the time of the Commission's review in March, 1985 Opengate used three devices which met the definition of restraints: the standard camisole, hand restraints, and a restraint chair.

The second restraining device, in addition to the camisole, was a set of hand restraints referred to as "hand restrictors" by Opengate staff. The hand restraints consisted of two heavy, adjustable, plastic cuffs which were linked by a double-eye hook. The cuffs were fastened to the wrists and secured with the clip. In effect, the hand restraints resembled police handcuffs.

The third device, referred to by Opengate staff as a "restraint chair" or "time out chair" was a high-backed chair with arm rests. Cuffs similar to those used as hand restraints secured both wrists and ankles to the chair.

At the time of the Commission's review in March, 1985, Opengate had not secured authorization from the Commissioner of OMRDD for the use of the restraint chair or the hand restrictors and thus, their use constituted an illegal form of restraint.

The absence of a physician's examination prior to placing a client in restraint, as was the standard practice at Opengate, circumvented one of the explicit safeguards provided by Mental Hygiene restraint law. While there is no evidence to suggest that a restrained resident at Opengate required and did not receive the services of a physician, the Commission's reviews of sudden deaths of clients in or following restraint caused grave concern that the inability of Opengate to meet the

unanticipated physical needs of agitated clients placed these persons at risk.

Multiple Aversives and Informed Consent

Also troublesome, although not expressly forbidden by statute or regulation, was Opengate's practice of using two or more aversives simultaneously. It was not uncommon for Opengate to concomitantly employ the use of restraint and an aversive. As noted earlier, Laura Smith was secured in a restraint chair and required to wear a helmet with an opaque face plate. Similarly, Linda Thompson was restrained and forced to inhale ammonia fumes and Roy Barton was restrained, forced to inhale ammonia and sprayed with water mist.

In each of the four case records examined, Opengate had moved beyond using a single aversive to reduce a maladaptive behavior to the use of multiple aversives. This phenomenon demonstrated the reinforcing nature of the aversives on the person administering them. The absolute power of the staff and the reciprocal powerlessness of the client, combined with the apparent success of aversives in reducing the targeted behaviors, easily leads to the "more is better" way of thinking. As commonly recognized, aversives are potently reinforcing to the person administering them. This clearly places clients at risk, and highlights the importance of informed consent from client (when possible) and family for specific aversive procedures.

Evidence gathered from the sampled case records, from discussion with the Executive Director of Opengate, and from family members suggested that *informed* consent was not secured from clients or family. Understanding the exact nature of the aversive, the conditions under which it would be applied, the consequences of applying and withholding the aversive, and alternative measures for reducing the maladaptive behavior are requirements of informed consent in this context. At Opengate, family members were routinely required to sign a consent form granting permission to the facility to use physical and chemical restraints regardless of whether there was any specific plan or identified need to use the restraints. (As an aside, the consent form noted that the camisole would be used in accordance with state codes and regulations, omitting reference to Mental Hygiene Law.)

When questioned about the consequences of a family refusing to give consent for the use of restraint or aversives, Opengate's Executive Director noted that he did not feel required to secure consent, and that if a family strongly objected to these forms of "active treatment," the family would be offered the option of withdrawing their family member from the facility. This is not to say that families had no knowledge of the aversives used with their family members. Some parents had signed quarterly treatment plans which enumerated the use of the restraint chair and other aversives. They did so, in part, because they felt they had no choice — both in a practical sense and in a philosophical one. They had no choice because, as the Executive Director explained, their withholding of consent would make no difference. Consent or leave. Equally important, the parents felt

that aversives offered the only possible remedy for their children's disturbing behaviors.

This lack of pedagogical and residential alternatives made it easier for families to accept the facility's rule that they not visit their family members in residences and, hence, they never saw the restraint chair in the lounge area, for example. With informed consent undermined, the clients of Opengate were left unprotected by their natural advocates, family members.

In summary, at the time of the Commission's review in March, 1985, Opengate ICF had developed a system of treatment that relied in large measure on the use of aversives, restraint and seclusion. These measures were employed, at least in some instances, for behaviors that were not serious and before it had been determined that the behavior could not be modified by positive or less intrusive measures.

In addition, clients and families had failed to receive sufficient information upon which to grant informed consent for the aversive procedures. These findings and the supporting documentation were shared by the Commission in May, 1985 with Opengate's administration and board of directors.

May 1985 - January 1986: Period of Transition

In the weeks immediately following the Commission's May 1985 report, the Executive Director of Opengate responded with a strong attack on the Commission's findings and defense of the use of restraint and aversives. The June, 1985 response noted, " . . . the elimination of the resident's serious maladaptive and asocial behaviors is essential and requires an intensive, consistent and dynamic treatment program." Arguing that Mental Hygiene Law Section 33.04 did not apply to Opengate's use of the camisole because such use was part of treatment plan, defining the use of "hand restrictors" as time-out devices rather than restraint, and denying that the time-out room was ever locked, the Executive Director characterized Opengate's treatment as "an intensive effort in an environment that is both supporting and demanding".

The Opengate Board of Directors, shaken by the Commission's findings and unconvinced by their Executive Director's rebuttal, redirected the facility's philosophy of care away from the use of aversives. Strongly disagreeing with this change and convinced that restraint and aversives were not only appropriate but essential behavior modification techniques for some Opengate clients, the Executive Director resigned. In August 1985,a new Executive Director took over leadership of the facility and, with the full support of the Board, and with substantial technical assistance from the OMRDD, began the process of staff re-education, of recommitment to sound pedagogical principles, to behavior modification through positive reinforcement and to the building of open and trusting relationships between staff and residents and between staff and parents. New professional personnel were hired and those professionals who could not or would not abandon punitive treatment measures were terminated or resigned. Effective December 11, 1985,

all aversive and physical restraint programs were eliminated at Opengate.

Staff of both the OMRDD and the Commission, on follow-up visits, chronicled the dramatic changes at the facility: restraint chairs were no longer in dayrooms and program areas; there was no evidence of time-out helmets or a seclusion room. A review of the treatment records of residents who had previously been subjected to restraints and aversives revealed that these interventions were no longer used. Equally important, the case records now reflected a focus on the acquisition of new skills. Appropriate learning goals and objectives had been developed for each of the sampled residents. To the edification of staff and to the delight of families, the maladaptive behaviors of the residents, previously characterized as intractable and responsive only to aversive measures, were decreasing in frequency and intensity in response to such interventions as the reinforcement of appropriate behaviors and the ignoring of inappropriate behaviors. As an example, Lara Smith, at the Commission's follow-up visits in January, 1986, was being reinforced for not picking her face by allowing her, at the end of a day during which she had not picked at herself, to telephone her mother and chat for a few minutes. Lara's face was almost clear of lesions and she spontaneously told Commission staff how happy she was.

Lara's spontaneous speech was indicative of a pervasive change in the atmosphere of the facility that was as real as the changes in treatment plans. Residents no longer "hung back" avoiding contact with unfamiliar CQC staff. Residents were calmer, showing fewer signs of apprehension, such as hand-wringing and finger-tapping, and appropriate and friendly physical contact passed between staff and residents.

Commission staff found, during their November, 1986 follow-up review, that residents' behaviors were continuing to respond to the emphasis on skill-building, the focus on appropriate behavior and the sense of being valued which came from interacting with caring staff. A priceless by-product of this facility's change was the improved relationships a number of residents were able to enjoy with their families.

CHAPTER II
OMRDD Certification and Oversight

Any discussion of why Opengate, Inc. was allowed to operate a program where restraint was used in clear violation of Mental Hygiene Law and where aversives were becoming an increasingly integral component of the treatment program must consider multiple factors. These factors include the inconsistency between OMRDD policies on the use of restraint, which forbid the use of the camisole with the developmentally disabled (OMRDD Policy and Procedures §5.5.2), NYS Codes, Rules and Regulations governing ICF-MRs, and Mental Hygiene Law which allows the use of a camisole to protect a client from harming himself or others (MHL §33.04); the apparent reluctance of the OMRDD to forbid the use of restraint in the face of strong opposition from families of clients at the facility who firmly believed this technique was improving their loved ones' behavior; and the dearth of programs in New York State willing to accept difficult multiply-disabled clients, and the consequent reluctance of the OMRDD to risk decertifying a non-compliant program and finding alternative placements for the 33 young adult residents. Finally, the ICF's use of aversives must be placed within the context of existing regulations/guidelines which are incomplete and uncomprehensive.

Restraint: The Chronology of Oversight

As early as June, 1981, the OMRDD certification team noted that Opengate was using a camisole to restrain clients. A second review team in December, 1981, reaffirmed the earlier findings that the facility was using the camisole in clear violation of OMRDD policy §5.5.2. The following month, the OMRDD wrote to the Executive Director of Opengate, citing among others the following deficiencies:

- The majority of the restraints used were part of a behavioral program and the treatment plan reflected this methodology. This aspect of the program at Opengate is in conflict with Mental Hygiene Law §33.04 (b), (d) and (e) which does not provide for the systematic use of restraints as a treatment modality.
- The restraint form did not include documentation of vital signs, such as pulse or blood pressure, to ensure an assessment of the patient's physical condition .... Mental Hygiene Law §33.04 (e) requires that a physician be immediately summoned if restraint is required. If a physician cannot attend within thirty minutes, this is recorded in the client's record, along with the reasons why.... In the records we [OMRDD] reviewed, the restraint was verbally approved by the physician. We did not see the actual written orders for restraint.

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The letter concluded asking Opengate to amend its policies regarding restraint to bring them into compliance with OMRDD policies and Mental Hygiene Law. Finally, the OMRDD cited several other New York State programs which also treated behaviorally impaired clients and suggested that Opengate might receive assistance in developing alternate program strategies from these programs and from OMRDD central office and regional office staff.

In response to this letter, the Opengate attorney countered in a February 22, 1982 meeting with OMRDD administration that the OMRDD policies applied only to "department facilities", i.e. developmental centers and not to voluntary agencies. Opengate concluded then that the OMRDD had no authority to forbid its use of the camisole. In order to clarify this matter, a meeting was held between Opengate and its attorneys and the OMRDD Commissioner and his senior staff. This exchange clarified that, in fact, OMRDD policies were not applicable to Opengate, that the OMRDD restraint policies were incongruent with Mental Hygiene Law on restraint, and underscored the need for the Office to develop policies on mechanical restraint aligned in spirit and substance with the Mental Hygiene Law — a task the OMRDD undertook shortly thereafter, which resulted in the promulgation of revised draft regulations on the use of mechanical restraints for review and comment in April, 1982.

While the exchange between Opengate and the OMRDD between June, 1981 and March, 1982 clarified the need for the OMRDD to develop policies regarding the use of mechanical restraints that would be applicable to all of its certified programs, it did nothing to change the situation at Opengate. Clients were still being placed in camisoles, both in truly emergency situations and as specified in their treatment plan as described in Chapter I. Also unchanged was the practice of placing clients into restraint without the benefit of a physician's physical examination.

In late September, 1983, the recently appointed Deputy Commissioner, Division of Quality Assurance, under a new OMRDD Commissioner, turned his attention to Opengate's continuing violation of Mental Hygiene Law §33.04 governing the use of restraints. Based on data collected during an April 15, 1983 review of Opengate's use of restraint made by OMRDD ICF/MR Survey Bureau staff, he wrote to the Opengate Executive Director instructing the facility to file a plan of correction no later than October 28, 1983 "which [would] modify the facilities' use of restraint to meet the spirit and intent of Mental Hygiene Law §33.04." The body of that correspondence noted that dialogue between the OMRDD and Opengate had been on-going for three years, and linked the OMRDD's concern to both the frequency of the use of restraints and to the "lack of documentation to show that restraints were only used when necessary to prevent serious injury and when less restrictive techniques were insufficient to avoid such injury."

Opengate responded quickly in a detailed and caustic letter dated October 14, 1983, which closed with the demand

to the OMRDD Commissioner that he issue a written retraction and formal apology "for the false and defamatory allegations" made by the Deputy Commissioner. Within days, the OMRDD Commissioner began receiving angry letters from families with relatives at Opengate. Indeed, the parents of some of the children on whom the camisole was regularly used wrote in defense of Opengate's use of restraint, sharing their perception that the restraints were the source of the decrease in maladaptive behaviors and of the increase in self control that they saw in their developmentally disabled children. In the face of such an outcry, and lacking alternative placements for the 33 residents of Opengate, the OMRDD fell silent. Opengate continued to use the camisole as it had for the last several years, and embarked on the wider application of additional aversive techniques such as water mist, ammonia capsules and cold showers.

Four months after the OMRDD's strong letter to Opengate instructing the agency to bring its restraint practices into compliance with the spirit and intent of Mental Hygiene Law §33.04, the Director of the Westchester Developmental Disabilities Service Office (regional office of OMRDD) in a letter to Opengate's Executive Director dated February 24, 1984, reversed the course of the OMRDD's compliance efforts and gave explicit permission for the use of the camisole with Sam Levine for a period of ninety days. That correspondence also noted that the DDSO would monitor the use of the camisole monthly during the ninety day period. No such monitoring ever took place.

OMRDD Oversight: From Confusion to Capitulation

Central to the OMRDD's failure to effectively monitor and modify the restraint practices at Opengate is the disparity between OMRDD policies on the use of aversives, New York State ICF regulations and Mental Hygiene Law. Both policies and regulations, the former because they are too restrictive and the latter because they are too liberal, are inconsistent with the Mental Hygiene Law. Policies, applicable to department facilities only, forbid the use of the camisole under any conditions. Regulations, on the other hand, permit the use of restraints as part of a treatment plan, whereas Mental Hygiene Law specifies emergency situations threatening danger to self or others as the only appropriate circumstances for the use of restraint. The OMRDD's failure to grapple forthrightly with these discrepancies and amend its regulations left at risk not only the residents of Opengate, but the residents of any other voluntary program which might view the use of physical restraining devices as an efficient, staff-sparing behavior management technique. While the OMRDD issued revised draft regulations (for comment) on the use of restraining devices in early 1982, as of February, 1987 final revised regulations had not yet been issued and promulgated.

Further complicating the regulatory morass, recent regulatory reform, specifically Part 624 of New York State Rules and Regulations dealing with incident

reporting, eliminates the requirement that facilities notify the OMRDD of restraint incidents. These regulations further offer still another definition of restraint and set no parameters for its appropriate use. Indeed, these regulations clearly indicate that it was not the OMRDD's intent in Part 624 to speak definitively on the appropriate use of restraint with developmentally disabled residents of OMRDD certified facilities. The present level of confusion about mechanical restraints, coupled with the elimination of the need to report the use of restraints, raises the likelihood of an increased incidence in the use of restraints with a concomitant increase in the possibility for misuse. While the OMRDD did not revise standards and regulations to safeguard residents of Opengate and other voluntary agencies from the misuse of restraints, it also failed, in the midst of heated debate about Opengate's use of the camisole, to monitor how the facility actually used the devices with specific clients. As noted earlier, in April 1984, the OMRDD gave permission to Opengate to use the camisole with Sam Levine, ostensibly mitigating this permission by assurances that it would monitor Opengate's use of the camisole with this resident during the 90 day permission period. In the face of the OMRDD's failure to provide any oversight of the facility's practices, Mr. Levine was restrained repeatedly not for just for 90 days, but for a period of eight months.

Failure to move beyond a paper review of Opengate's restraint procedures and to look at how they were implemented with specific residents set the stage in January, 1985, for the OMRDD, during the course of a certification inspection, to approve Opengate's expanded aversives program. Such approval would seem to indicate that the OMRDD did not carefully review residents' records where it was documented that innocuous behaviors (as illustrated in Chapter 1) were responded to with uncomfortable and sometimes painful events. It would also suggest that reviewers did not observe first-hand the use of tickling to insure the inhalation of ammonia fumes, or the placing of a resident in a "restraint chair" or the concomitant use of the hand restrictors and the modified helmet. Given the restrictive and painful nature of the restraints and aversives, and the history of Opengate's defiance of legal safeguards protecting residents from abuse and misuse of restraint, the OMRDD did not exercise its oversight responsibilities diligently.

Conclusion

The excesses practiced by Opengate in an effort to contain the behaviors of its residents illustrate the potent lure of the behaviorists' quick fix. Simply stated, persons change their behavior (at least temporarily) when faced consistently with painful and unpleasant consequences. Exhilarated by their success, and "caught" by the highly reinforcing effect of rapid and dramatic changes in residents, staff are less and less likely to question the legal, ethical and moral implications of their actions. Soon the issues of proportionality,

client and family involvement in the approval and selection of behaviors to be modified and methods to be used, primary dependence on positive methods of change and other related considerations seem somehow academic and the need to "treat at all costs" becomes overriding. At this point, in the absence of clear guidelines and strong external oversight, programs are likely to cross the line from aversive to abusive. Vigilant external oversight supported by clear, explicit guidelines are essential to protect the residents of programs which embark on this and any other controversial and/or experimental method of treatment. As explicated earlier, New York State presently lacks the consistent and comprehensive guidelines upon which to build an effective monitoring mechanism.

Present regulations state that aversive methods may be used to modify dangerous behavior when less drastic techniques have failed and after securing the consent of the client and the facility's Human Rights Committee. But the regulations are silent on what constitutes informed consent and on the composition and operations of the Human Rights Committee. Finally, the regulations fail to require parties external to the facility to review treatment involving restraint or aversives, a safeguard borrowed from the medical model, and now common for experimental treatments or treatments particularly subject to abuse.

Recommendations

The Commission recommends that appropriate sections of Title 14 New York Code, Rules and Regulations be amended to ensure adequate safeguards for the use of restraint and aversives as part of the treatment of developmentally disabled persons.

Any revision of regulation should clearly articulate that the use of these interventions is discouraged and is seen as a last resort to deal with behaviors which pose serious threat of harm to self or others. Additionally, regulations should establish a process whereby the planning and implementation of a course of treatment involving the use of aversives will be subject to internal and external scrutiny at regular intervals.

In order to insure adequate safeguards for clients, the Commission recommends that:

- Facilities contemplating using aversives as part of behavioral treatment should, on a client-specific basis, secure the consent of the client if competent to provide consent, or of appropriate members of his family or legal guardian, as well as authorization from the facility's senior management and Human Rights Committee. (Such committees should consist of professionals and well-informed lay advocates and should include members not affiliated with the institution).

  As part of this consent or authorization process, clinicians at the facility should demonstrate that the client's specific behaviors subject to these treatment interventions pose serious danger to self or others and that less severe interventions have been proven or deemed to be ineffective. Furthermore, the clinicians propos-

ing the plan, the staff scheduled to implement the plan, as well as those offering consent or authorization should experience the proposed restraint or aversive for the duration called for in the plan. The facility administration must certify that all staff participating in the treatment program have had adequate training in the specific techniques to be used and in related areas; e.g., handling any emergencies that might arise as a result of the implementation of the plan.

- Permission for the use of these interventions as part of a behavioral treatment program for any client should also be secured on a case-by-case basis from a body external to the facility, appointed by the Office of Mental Retardation and Developmental Disabilities. (To ensure the timeliness of the permission granting process, external approval committees should be established on a regional basis and a procedure created for expedited review when warranted). Using Article 24-A of the Public Health Law as it applies to human research as a model, such committees should be comprised of individuals with considerable experience in the area of behavior management as well as parents or relatives of developmentally disabled persons.
- Permission by the external body should be given only after it has been satisfied that the facility has demonstrated by clear and convincing evidence the dangerousness of the targeted behavior and the ineffectiveness of other treatment interventions. While the permission process must be prompt, the review process must be complete and carefully thought out. The permission process must require that the facility's plan specifies, at a minimum, the current problem behavior, its dangerousness, the ineffectiveness of other interventions, the planned interventions, persons who will employ them, and the intended benefits. Data related to the use of the planned intervention must be collected by the facility: Did the problem behavior increase or decrease? Who actually applied the restraints or aversives? When? For what actual duration, frequency, and intensity? What side effects, positive and negative, were noticed? What non-aversive procedures were tried at the same time? These plans and results of actual usage must be reported to and reviewed by the external body periodically and, in any event, prior to authorizing the continued use of the restraint or aversives. Additionally, the information collected by the external body and its determinations should be reported to the Central Office of OMRDD so that such can be reviewed and used in the future on a State-wide basis to help make better decisions and recommendations in the permission process.

Permission must be time-limited, with each succeeding request for the same

client being for shorter and shorter duration. For example, the original request may be granted for a maximum of 30 days, the second request may be granted for up to 15 days, and any further requests may be granted for up to seven days at a time. The shorter successive time frames would help to assure greater scrutiny of the restraint or aversive procedure and its apparent failure with continued use. The regulations should specify roles and qualifications of staff involved in designing and implementing programs calling for the use of restraint or aversives to ensure that from a medical point of view, the client is "cleared" for the procedure and will be monitored by sufficiently trained staff, and that from a behavioral point of view, the intervention is appropriate and that staff are proficient in its application.

- The OMRDD in conjunction with the Department of Social Services and the State Education Department should forbid the use of certain particularly painful and/or dangerous aversives and the concomitant use of two or more aversives. The withholding of food (in the same form served to other residents of the program) and the withholding of sleep should also be expressly forbidden.

APPENDIX A
Response of Office of Mental Retardation and Developmental Disabilities

APPENDIX A

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 12229

ARTHUR Y. WEBB
Commissioner

June 2, 1987

Mr. Clarence J. Sundram
Chairman
Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue, Suite 1002
Albany, New York 12210

Dear Mr. Sundram:

OMRDD staff have reviewed the Commission's final report issued May 5, 1987 regarding the misuse of restraint, seclusion and aversives at Opengate ICF. OMRDD has recognized the need for revising its regulations regarding the authorization and use of Behavior Management Techniques, which were the subject of your report. This is a very complex issue which we take very seriously.

I would emphasize that it was through our regulatory process that concerns regarding the thoroughness of our regulations regarding behavior modification and aversive conditioning were initially noted. The Commission's initial report on Opengate reemphasized these concerns. Senior OMR management staff and the Board of Directors of Opengate met in August, 1985. At this meeting, OMRDD clearly stated an imperative for Opengate to revise their clinical approaches and treatment modalities. Opengate's Board agreed to implement this imperative contingent upon receipt of technical assistance from OMRDD. As your current draft reports, technical assistance was provided and the revision has been accomplished.

Due to our concerns, OMRDD staff have had several meetings with CQC staff for the purpose of reviewing, on a line by line basis, the material to be included in Part 633.16 which will address the topics of behavior management and the use of aversive procedures. These meetings have been most cooperative and resulted in a consensus by both parties that the material addressed the major CQC concerns.

Our regulatory agenda calls for the filing of a proposed agency action that will address various techniques of altering/modifying/controlling maladaptive or inappropriate behavior. This will be incorporated in Part 633, in which OMRDD has been addressing the important area of client protection. It is anticipated that Section 633.16 that addresses techniques to manage client behavior will be sent out as a proposed agency action by early fall. We believe that many of the CQC's recommendations will be addressed at that time (e.g., limiting the qualifying condition for their use). However, the specificity of some of the Commission's suggestions is overly restrictive and extends beyond the scope of regulations. This is in conflict with this agency's 5.07 plan commitment to ensure that compliance with regulations is not burdensome for providers yet protects client rights and ensures quality care.

Our response to CQC's recommendations, beginning on page 34, is as follows:

- We support the need for consent before such techniques are utilized. The approval by an internal review committee (such as Human Rights) is

warranted. We support the other concepts set forth except that requiring authorization from facility senior management on client by client basis for the use of aversives is inappropriate. This is an overall agency/facility decision and the limitations should be set by their own policy. In addition, requiring regulatory compliance with the concept that all who consent to or authorize the use of aversives must experience the aversive would be beyond the purpose of regulations and be difficult to enforce. The advancement of this concept would appear to be more appropriately met through guidelines in this area.

- The recommendation that the use of aversives and restraining devices be subject to internal and external scrutiny is a point to be considered; however, it is doubtful we would or should entertain the idea of a separate committee formed under OMRDD's auspices to review every use of aversives or restraining devices at regular intervals. We must consider that there are different levels of aversives as well as the responsibilities of licensed individuals before we make any sort of commitment to include a requirement such as this in regulation, we need to evaluate the entire picture.

- Except for the inclusion of the external review body, the proposed regulations will be consistent with the basic concepts you have presented. Much of the detail, however, is best left for dissemination via policy or administrative memo.

- It is agreed that permission to use such techniques needs to be time limited. Currently, it is proposed that such approval not exceed three months. CQC's specificity on time frames is too restricting. Time frames must be based upon the individual client's program and not by some predisposed formula. We do concur that the staff implementing such a program be accountable for monitoring its impact on the problem. We are proposing regulations which will indicate that involved staff are to be adequately trained. The degree of specificity for adequate training will be reviewed prior to promulgation.

- OMRDD is currently participating in a project under the auspices of the Council on Children and Families to address behavior management issues on an interagency basis. OMRDD's draft regulations on the topic are being used as the basis for discussion. With regard to separate statements about withholding of food or sleep, the food concerns are addressed in Part 633 in a section on client privileges; the denial of sleep and food need not be individually addressed, as such a "technique" is not allowed by regulation and would be considered "client abuse."

We appreciate the continued collaborative efforts between the agencies. We will take your recommendations under advisement and evaluate them in relation to the management of all programs, not just Opengate.

Sincerely,

Arthur Y. Webb
Commissioner

AYW/TJC

APPENDIX B
Response of Board of Directors, Opengate, Inc.

APPENDIX B

HAROLD AUERBACH
835McLean Avenue
Yonkers, New York 10704

June 4, 1987

Clarence J. Sundram, Chairma
Commission on Quality of Car
For the Mentally Disabled
99 Washington Avenue, Suite 002
Albany, New York 12210

Dear Mr. Sundram,

Thank you so much for sending me a copy of the report regarding the prior misuse of aversive behavior modification techniques at Opengate.

In the spring of 1985, when a number of Opengate board members and I became increasingly aware of the harmful policies being pursued by the then Executive Director I was elected Chairman of the Board. Our intention was to put an end to these harmful policies by forcing the resignation of the Executive Drector, which we were able to accomplish within a short period of time. With the hiring of a new Executive Director, and with considerable help from State agencies, we were able to change direction and begin the process of eliminating aversives at Opengate.

We are most grateful to you and to Commissioners Platt and Cashen for providing the impetus which enable us to change Opengate's philosophy and direction. We wish to take this opportunity to extend our thanks to the Commission for its help and guidance during a difficut transitional period.

Opengate serves a seveely handicapped population, and shall continue to do so. We are proud of Opengate's accomplishments in modifying the maladaptive behaviors of the residents without the use of aversives. Again, we thank you for your involvment and assistance.

Sincerely,

Harold Auerbach
Chairman of the Board
Opengate Residential Habilitation
and Treatment Center

HA/a

cc: Commissioner Irene Platt